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The Model Reporting Area

FOR BLINDNESS STATISTICS



**PURPOSE
DEVELOPMENT
STANDARDS
PROGRAM**

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Public Health Service

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- Purpose
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Prepared as a joint publication of the Model Reporting Area for Blindness Statistics and the National Institute of Neurological Diseases and Blindness

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FOREWORD*

“It is a curious paradox that while the blind have always been with us we know so little about them. The year 1962 may well prove to have been a turning point in the long and frustrating struggle to determine the magnitude of the problem of blindness, the causes of this disability, and the characteristics of the afflicted. Censuses, surveys, and projections of reported blind from a limited geographic area to the nation as a whole, have all been used from time to time. The problems of definition and lack of reliable medical information from respondents make it hazardous to use census or survey data for estimates. The sampling error inherent in projecting the data from one State to the entire country would make this approach infeasible.

“In 1962 a group of States determined to do something about the vexing problems created by lack of adequate statistics on blindness. They banded together in common purpose as the Model Reporting Area for Blindness Statistics and agreed, for statistical reporting reasons, to use a common definition of blindness, to collect certain essential information on each new case added to the register, to use the Standard Classification of the Causes of Blindness, and to keep their registers up to date. What this high resolve means for the cause of good statistics on the blind one can only guess. However, there is no gainsaying the fact that by speaking the same language, by agreeing to produce comparable and poolable data, the Model Reporting Area States are meeting a problem with action calculated to give the nation for the first time urgently needed information on an age-old disability. This information will guide decision making and bolster confidence in action taking.

*Excerpted from Foreword to Proceedings of the First Annual Conference of the Model Reporting Area for Blindness Statistics, 1962.

“ . . . agreeing to agree also carries certain responsibilities of which the States are well aware. It is hoped that sharing these responsibilities will, in the years to come, be a source of gratification to more than the 11 States that comprise the nucleus of the Area.”

RICHARD L. MASLAND, M.D.,
*Director, National Institute of
Neurological Diseases and Blindness.*

MODEL REPORTING AREA

Statement of Purpose

To meet the increasing need for uniform, reliable, and comparable statistics on the problem of severe visual impairment among the Nation's population, the National Institute of Neurological Diseases and Blindness (NINDB), with the counsel and cooperation of the National Society for the Prevention of Blindness, the American Foundation for the Blind, and the Division of Chronic Diseases of the Public Health Service, sponsored the organization of a Model Reporting Area for Blindness Statistics (MRA). This Model Reporting Area is a voluntary association of States which maintain registers of blind persons, and which have joined together in a pioneering and cooperative effort to collect uniform information so as to arrive at comparable and meaningful statistics on blindness of benefit to the States themselves and to the Nation as a whole.

The two basic objectives, to which each member State subscribes and agrees to uphold, are to make better statistics available on blind persons and to stimulate research in the field of blindness. In order to accomplish this, the MRA will:

1. Encourage complete reporting of the blind, so that the number registered may more nearly reflect the true prevalence of blindness, and so that additions to the registers may more nearly reflect the true incidence;
2. Seek to improve the records concerning the reported blind, so that the causes of blindness and the characteristics of the blind may more easily be studied;
3. Use a common definition of blindness and standardize recording of essential information, so that data from different States can be more meaningfully compared or pooled in an effort to arrive at national statistics on blindness;

4. Disseminate statistics derived from the registers, so that data may be readily available to all who are interested in the problems of blindness.

Efforts will be made to aid and encourage other States throughout the country to meet the standards for membership in the Model Reporting Area for Blindness Statistics, so that they may each play a greater and more significant role in helping to determine the extent and nature of blindness as a national health problem, with ultimate benefits for the prevention, control, and treatment of blindness.

DEVELOPMENT OF THE MODEL REPORTING AREA

Since 1830, repeated efforts have been made to obtain reliable national statistics on the number and characteristics of blind persons. However, figures derived from each of the 11 decennial census enumerations between 1830 and 1930, and from the National Health Surveys in 1935–36 and in 1957–58, proved to be inadequate. Problems of definition and enumeration led to statistics which were inaccurate, incomplete, or of limited value. Based as they were on family interviews, these sources could not provide information on legally or clinically defined blindness. Furthermore, all such efforts to obtain information on the Nation's blind population were confined to prevalence—i.e., the number of living blind at a given time; and in no case were attempts made to obtain equally important national figures on incidence—i.e., the number of new cases of blindness occurring during a year or other period of time.

Utilizing the rather complete register of blind persons maintained by the North Carolina State Commission for the Blind, Dr. Ralph G. Hurlin arrived at estimates of blindness prevalence, by State, as of July 1, 1952. Although this formed the basis for the most widely used, and perhaps most meaningful, national estimates of blindness, the limitations of projecting the findings from a single State to the entire country were apparent.

Encouraged by Dr. Hurlin's work, and recognizing the continued need for uniform and reliable statistics on the incidence, prevalence, and causes of blindness, the Biometrics Branch of the National Institute of Neurological Diseases and Blindness considered the feasibility of utilizing existing registers of the blind throughout the country to satisfy this need. The existence of reporting laws and registers of the blind in many States did not

in itself insure uniform and reliable statistics, since many problems, such as a uniform definition of blindness, would have to be worked out. However, the existence of the laws and registers did suggest a means by which such statistics could be achieved. It was thought that States maintaining blindness registers would be willing to agree to collect certain specified data on each blind person and make concerted efforts to keep their registers up to date. In March 1961, a Planning Group for the Model Reporting Area—consisting of members of the National Society for the Prevention of Blindness, American Foundation for the Blind, Division of Chronic Diseases of the Public Health Service, and the Biometrics Branch of the NINDB—was called together and it unanimously approved the idea of a Model Reporting Area.

Staff of the Biometrics Branch then visited each of the 39 States thought to have registers of the blind. Thirty-five States did, in fact, have blindness registers, although a number of these were not considered to be sufficiently adequate. Interest in the idea of a Model Reporting Area was extremely high in the State agencies. Information gathered on these visits was presented in September 1961 to the Planning Group which approved a set of objectives and standards for membership.

In accordance with the approved standards, and based on information obtained by staff visits to each State agency concerned, as well as on information secured by questionnaire from these agencies, an evaluation of each State's capacity and willingness to satisfy the MRA standards was made by the Biometrics Branch. The evaluations, submitted to the Planning Group, constituted the basis for acceptance of 11 States into the Model Reporting Area. It later became necessary for two of these 11 States to withdraw from the Area due to staffing difficulties and administrative priorities, although they still maintained an active interest in the objectives of the Area. The nine remaining member States comprise about 14 percent of the total United States population.

The First Annual Conference of the Model Reporting Area for Blindness Statistics was held in Bethesda, Md., in March 1962. To this organizational conference were invited from each of the 11 original member State agencies maintaining the blindness reg-

ister, the administrator and the person in charge of the daily maintenance of the register. Also invited were representatives of the American Foundation for the Blind, the National Society for the Prevention of Blindness, the Canadian National Institute for the Blind, and various Federal agencies with blindness programs. Matters covered at the Conference included the organizational structure of the Model Reporting Area, need for good blindness statistics, register problems among the member States, research potential of blindness registers, register maintenance, formal adoption of the standards for membership, items of information to be uniformly collected, and the nature of tabulations to be prepared annually. In addition, representation of the member States on the Planning Group was provided for on a rotating basis.

Where a State maintaining a blindness register cannot meet the standards for admission to the MRA, consultative and other services of the Biometrics Branch are available, upon request, to assist it in meeting the standards. The Biometrics Branch's services are also available to any State that does not now have a State-wide register to assist it in setting up a register to be maintained by a single State agency. Such assistance is now being provided to a number of States, representing an additional 11 percent of the total United States population, and several of these States are expected to become members of the MRA in the near future. It is hoped that through such efforts, and as more States see the great advantage to themselves as well as others in the collection of uniform statistics, the Model Reporting Area will grow.

Statistics secured through the Model Reporting Area will be made available to State, national, voluntary, and other interested agencies.

STANDARDS FOR MEMBERSHIP IN THE MODEL REPORTING AREA

. . . and Procedures for Application

STANDARDS

I. Membership

The Model Reporting Area for Blindness Statistics is a voluntary association of States which maintain registers of persons with serious visual impairment, and is organized under the sponsorship of the National Institute of Neurological Diseases and Blindness. (For convenience, the MRA defines the term *blindness* to include *serious visual impairment* as described in III below.) Each member State has agreed to uphold the standards for membership, and may continue in membership as long as it upholds them. Periodic evaluation of the performance of each member State will be made by the NINDB in order to insure maintenance of these standards.

II. Objectives

Each member State subscribes to the two basic objectives of the MRA, which are: (1) to make better statistics available on blind persons, and (2) to stimulate research in the field of blindness.

III. Definition of Blindness

Each member State accepts for statistical purposes the MRA definition of blindness, which includes serious visual impairment as follows: "Visual acuity of 20/200 or less in the better eye, with best correction; or visual acuity of more than 20/200 if the widest diameter of the field of vision subtends an angle no greater than 20 degrees." Individuals with a progressive eye condition which

does not yet meet the MRA definition are excluded. As understood here, the term *best correction* does not include devices which cannot be used continuously or which improve visual acuity to more than 20/200 only by restricting the field of vision to 20 degrees or less.

IV. Scope of Register

Each member State will attempt to include on its register all residents who fall within the MRA definition of blindness. Such registrants will constitute its MRA Register. The State may also register other persons under a wider definition of blindness, but only if these persons can be easily distinguished for statistical purposes. The MRA Register will not be confined to persons who have applied for services; nor will there be any arbitrary exclusion of persons on the basis of age, race, or any other factor outside the criteria of the MRA definition of blindness.

V. Essential Items of Information

Each member State will attempt to collect all of the items of information listed below for each registrant. It will routinely make efforts to clarify ambiguous reports, and to obtain the data missing from incomplete reports. The required items must appear on the register card (or its equivalent) for ready access. These items are the essential minimum; however, States are encouraged to collect additional pertinent information.

A. *Date of Addition to the MRA Register*

This includes year and month. Where the State's total register includes persons who do not fall within the MRA definition of blindness, the date of addition to the MRA Register must not be confused with the date of addition to the total register. Also, the date of addition to the register must not be confused with the date of referral to the agency.

B. *Type of Addition to the MRA Register*

This means that first additions to the MRA Register within a State must be distinguished from readditions of persons previously on the MRA Register in that State.

C. *County of Residence* (or its equivalent)

D. *Date of Birth*

This includes year, month, and day.

E. *Sex*

F. *Race*

This item must be so recorded as to permit classification into four categories: white, Negro, Indian, other. However, it may be omitted where recording such information is contrary to law.

G. *Age at Onset*

This item refers to the probable age of the registrant at onset of serious visual impairment. The exact age should be recorded where known, and in particular registrants who were blind at birth should be so recorded, but otherwise an approximation will suffice.

H. *Date of Eye Examination*

This includes year and month.

I. *Discipline of Examiner*

This item refers to the person responsible for the most recent eye examination report on file. It must be so recorded as to permit classification into four categories: ophthalmologists and eye-ear-nose-and-throat specialists, other physicians, optometrists, others.

J. *Degree of Vision*

Degree of vision in the better eye, with best correction, must be so recorded as to permit classification into the MRA Vision Groups as follows:

- 0 Absolute blindness (no light perception)
- 1 Light perception only (faulty light projection)
- 2 Accurate light projection only
- 3 Motion or form perception, but visual acuity less than 5/200; counts fingers only at less than 3 feet
- 4 5/200 up to but not including 10/200; counts fingers at 3 feet up to but not including 10 feet
- 5 10/200 up to but not including 20/200

(Continued on next page)

- 6 20/200
- 7 Better than 20/200, but field restricted to 20 degrees or less
- 8 Unable to determine exact degree of vision, but presumed within the MRA definition of blindness
- 9 No report as to exact degree of vision, but presumed within the MRA definition of blindness
- X Not within the MRA definition of blindness (for persons registered under a wider definition of blindness)

If the exact visual acuity is not specified on the register card (or its equivalent), then it must be specified in readily-available auxiliary records; and if the visual acuity exceeds 20/200, then the restriction in visual field must be specified also.

K. *Standard Classification of the Causes of Blindness*

This item includes both the complete 3-digit code for site and type of affection and the complete 4-digit code (including supplementary classification) for etiology. Coding of cause of blindness is to be completed for all cases within three years following admission of the State to the MRA. The most recent revision of the Standard Classification is to be used.

L. *Date of Removal from the MRA Register*

This includes year and month. Where the State's total register includes persons who do not fall within the MRA definition of blindness, the date of removal from the MRA Register must not be confused with the date of removal from the total register.

M. *Reason for Removal from the MRA Register*

This item must be so recorded as to permit classification into five categories: death, moved out of State, recovered vision, unable to locate, other. Where "other" is given as the reason, it must be specified.

VI. **Updating**

Each member State will continually correct the essential items on its register cards in accordance with any reports received of reinterviews or reexaminations of registrants. It will immediately remove from the MRA Register any person known to have

died, moved out of State, or recovered vision beyond the MRA definition of blindness. Furthermore, it will redetermine the residence and blindness status of every person on its MRA Register during an annual clearance. A registrant may be considered cleared if he has received any service for the blind or has otherwise been contacted since the beginning of the calendar year, provided that there is no evidence that his status has changed since then. However, intensive efforts must be made to contact all other registrants. Contact may be made by mail inquiry, telephone call, or personal visit to the registrant himself, his relatives or neighbors, his physician, or an institution in which he resides; a personal visit will be made, if feasible, when other methods fail. These intensive efforts will be completed before the end of the calendar year, and registrants who have not been located will be removed from the MRA Register by that time. It may then be assumed that those persons who remain on the MRA Register at the end of the calendar year are still resident in the State and still fall within the MRA definition of blindness.

VII. Tabulations

Each member State will prepare certain tabulations of data from its MRA Register for each calendar year, in accordance with the specifications of the NINDB, and will submit them to the NINDB by March 15 of the following year.

VIII. Preservation of Records

Each member State will preserve its eye examination reports and its register cards (or their equivalents) for the length of time that State policy permits.

IX. Amendments

These standards were drawn up by the Biometrics Branch, NINDB, in accordance with discussion at the First Annual Conference of the Model Reporting Area and were approved by the MRA Planning Group. Amendments to the standards may be made by majority vote of the member States, subject to the approval of the Planning Group.

PROCEDURES FOR APPLICATION

When an agency maintaining the State blindness register believes it can meet the above standards, and desires to be admitted to the Model Reporting Area, a formal request for membership should be made by the Director of that State agency to the Chief, Biometrics Branch, National Institute of Neurological Diseases and Blindness. Biometrics Branch staff will visit the agency concerned to review the register operations and to discuss the detailed requirements for membership. The Biometrics Branch will evaluate the information obtained at the visit and reach a decision regarding the agency's capacity to meet the standards. The Branch will then advise both the Planning Group and the applicant State agency of this evaluation and decision. If accepted for membership, the State agency's representative will be seated as a member of the Model Reporting Area at the next annual meeting. If not accepted for membership, the consultative services of the Biometrics Branch will be available, upon request, to assist the applicant State agency in meeting the standards for membership.

APPENDIX

TABULATIONS REQUIRED OF MODEL REPORTING AREA MEMBERS

Membership in the Model Reporting Area carries with it the obligation to complete specified tabulations of data from the blindness register on a calendar year basis. Such tabulations for a given year must be submitted to the Biometrics Branch, National Institute of Neurological Diseases and Blindness, by March 15 of the following year.

The tabulations required annually are as follows:

1. First additions by sex, age, race and degree of vision.
2. Readditions by sex, age, race and degree of vision.
3. Number registered as of December 31, sex, age, race and degree of vision.
4. Removals from register by sex, age, race and reason for removal.
5. Removals from register by degree of vision and reason for removal.

Annual tabulations planned for the near future include:

6. Additions by sex, age, race and major site groups.
7. Additions by sex, age, race and major etiology groups.
8. Number registered as of December 31 by sex, age, race and major site groups.
9. Number registered as of December 31 by sex, age, race and major etiology groups.
10. Additions by major site and major etiology groups.
11. Number registered as of December 31 by major site and major etiology groups.

In addition, periodically, special sets of tabulations may be completed along with the tabulations listed above. Revisions, addi-

tions, or deletions may be made by the Model Reporting Area to take into account changing conditions or to develop special studies.

MEMBER STATES OF THE MODEL REPORTING AREA

Date of Admission and Addresses of Blindness Agencies, 1963

CONNECTICUT (1962)

Executive Secretary
Connecticut Board of Education of
the Blind
State Office Building
Hartford 15, Conn.

KANSAS (1962)

Director
Services for the Blind
State Department of Social Welfare
State Office Building
Topeka, Kans.

LOUISIANA (1962)

Director
Division for the Blind and Sight
Conservation
State Department of Public Welfare
P.O. Box 4065
Baton Rouge 4, La.

MASSACHUSETTS (1962)

Director
Division of the Blind
Department of Education
The Commonwealth of Massachu-
setts
14 Court Square
Boston 8, Mass.

NEW HAMPSHIRE (1962)

Supervisor
Services to the Blind
Division of Welfare
Department of Health and Welfare
Concord, N.H.

NEW JERSEY (1962)

Executive Director
New Jersey State Commission for
the Blind
1100 Raymond Boulevard
Newark 2, N.J.

NORTH CAROLINA (1962)

Executive Secretary
North Carolina Commission for the
Blind
Mansion Park Building
P.O. Box 2658
Raleigh, N.C.

RHODE ISLAND (1962)

Administrator
Division of Services for the Blind
Department of Social Welfare
Harborside Park
1 Washington Avenue
Providence 5, R.I.

VERMONT (1962)

Director
Division of Services for the Blind
Department of Social Welfare
128 State Street
Montpelier, Vt.

Inquiries concerning individual State reporting systems should be sent to the correspondents listed above. General information about the Model Reporting Area and other statistical matters is obtainable from:

Chief, Biometrics Branch

NATIONAL INSTITUTE OF NEUROLOGICAL DISEASES AND BLINDNESS
National Institutes of Health, Bethesda 14, Md.

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